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Use of Behavioral Activation Theory to Identify Depression among HIV-Positive Women of Color in
the Rural South

by

Tascha R. Johnson

An undergraduate honors thesis submitted in partial fulfillment of the

requirements for the degree of

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in

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TITLE: Depression among HIV-positive women of color – a mixed methods analysis

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Abstract

Women of color (WOC) are disproportionately affected by the HIV epidemic in the Southern United States and are at increased risk of infection, mortality and being lost to care. It has been found that compared to Whites, WOC are more likely to have more negative views towards mental illness and are less likely to seek help. The research presented here considers how depression acts as a barrier to health care and discusses the challenge that WOC face in identifying and naming depression. The Behavioral Activation Theory, posits that women may show depression through their behaviors even if they don't explicitly name depression as an experience. Using behavioral activation theory, we attempted to 1) identify the likely prevalence of depression in WOC with HIV, even among those who may not verbally acknowledge being depressed and 2) use the actions, behaviors and verbiage used to describe an emotional state, to more accurately identify the occurrence of depression in these women. The project goal was to understand how depression affects care behavior among WOC with HIV using both quantitative (189 women were interviewed at baseline) and qualitative data collection (two focus groups consisting of 11 women total and 19 individual semi-structure interviews). From this study we learned that depression is an important barrier to women's ability to get into and stay in HIV care. This is important going forward for researchers and practitioners who seek to engage and retain WOC with HIV in care.

Key Words: women-of-color, WOC, HIV, depression, social support, Behavior Activation theory, African American, women

Background

African-Americans (AA) have the highest rates of HIV and AIDS of any racial/ ethnic group in the nation; they account for almost half of all new infections in the United States each year and constitute more than one-third of all people living with HIV. ^[1, 2] As of 2014, AAs make up 12% ^[1, 2] of the U.S. population and AA women, only 7% ^[1, 2] of the population, the incidence rate of HIV in African-American women is twenty times higher than that of white women, and almost five times higher than in Hispanic women.^[1, 3] While the number of new infections among African-American women has declined between 2005 and 2014, AA women still account for 13% of all new infections in the United States and nearly 64% of all new infections among women.^[3]

Previous studies have shown that African-American women face substantial barriers to accessing HIV health care.^[4-7] These barriers take on many forms including: confidentiality concerns, difficulty scheduling appointments, obligations to others,^[8-10] behavioral issues (i.e. drug addiction), interpersonal relationships (i.e. lack of social support, partner abuse) ^{[6] [11] [10]}, physical health concerns (i.e. comorbidities), transportation (i.e. not enough money for gas) ^{[9] [5] [8] [10]} and shame from HIV-related stigma ^{[6, 9] [4] [5]}. These barriers represent a unique experience to the African-American woman in accessing and engaging in health care.

Depression is commonly experienced by people living with HIV (PLWH) as a co-morbid condition. Related work reports depression as a barrier for PLWH, because it prevents them from obtaining and participating in care.^[4, 7, 12, 13] While depressive symptoms may be apparent if patients are specifically questioned, these may not be expressed or recognized as depression by either patient or provider if unquestioned.^[4, 7, 14]

Depression may also be a compounding factor for many PLWH.^[4, 7, 13] One of the difficulties in diagnosis of depression is the lack of recognition of the presence of depressive symptoms.^[4, 7, 13, 14] African American women have been shown to have a difficult time naming and discussing depression.^[4] Prior work has shown that cultural norms^[4, 12, 15] play a role in the difficulty that African-American women have in recognizing and reporting depression as compared to White women. It has been found that compared to Whites, women of color are more likely to have more negative views towards mental illness and are less likely to seek help.^[4, 13, 16, 17] In one study evaluating HIV disclosure, social support and depression among rural African-American women,^[4, 12] many of the women reported high levels of depressive symptoms upon entry into the study. But researchers found that 40% of those women had never been diagnosed with depression^[12] and of those who had been previously diagnosed with depression, nearly half (48%) were not receiving treatment.^[4, 12] Depression as a co-morbidity,^[4, 5, 13] contributes to the difficulty in obtaining healthcare,^[6] resulting in hopelessness, inertia, apathy and isolating behaviors. Therefore, understanding the correlation between depression and HIV may help practitioners identify those women who are at highest risk for experiencing it.

Prior work investigating factors associated with depression found a lack of social support,^[5, 11, 12] rural residence,^[12] and non-disclosure of one's HIV status,^[12] to be associated with depression. Further, partner abuse,^[11]^[18] drug abuse, low income and risky sexual behavior,^[10, 11, 18] have also been correlated with depression among PLWH. If we know that African-American women are challenged to identify depression by name, then we can use the behaviors of the women to help broaden the scope of depression identification and take a closer look at the factors associated with it. In addition to using the

PHQ-9 scale (which is used to quantify depression symptoms), the ability to use both quantitative and qualitative identification will help to more effectively identify when depression is present.

The Behavioral Activation (BA) Theory ^[19, 20] has been used to develop interventions for depression and hypothesizes that these correlating factors are not only co-occurring but are actually contributing to the development of depression and could be utilized in depression identification.^[19-21] BA Theory establishes depression as an aversive emotional response to a negative event (i.e. HIV+ diagnosis).^[19] ^[20, 22] This emotional response, then triggers self-destructive actions, which may be passive or physically destructive avoidance behaviors (i.e. sleep loss, avoiding social contact, increased use of drugs or alcohol).^[19, 20] It is these self-destructive behaviors, that if left untreated, may contribute to further emotional decline leading to clinical depression. Looking for these self-destructive, avoidance behaviors can help care providers identify when depression is present, even when it goes unrecognized by the patient. Using the BA Theory can help the care providers think more broadly about casting a wider umbrella in the diagnosis of depression based on the behaviors of the women of color living with HIV.

While the quantification of depression prevalence is useful, it only captures depression if women are able to name and willing to report. Qualitative data can help researchers understand the context in which reported depression occurs and may identify expressions of depression that are not named as such. Given our desire to understand both the prevalence and the way women of color experience depression, the purpose of this study was to 1) quantitatively describe the prevalence of depression among HIV-positive women in this study; 2) quantitatively demonstrate the correlates of depression; and 3)

qualitatively examine the factors that buffer or exacerbate depression among focus group respondents.

Methods

Study setting

The research reported here was conducted among Guide to Healing project participants in an academic medical care clinic in North Carolina (NC), which provided HIV care to 1700 HIV-infected people in 2010, of whom 58% were African American (AA), 10% were non-white Hispanic. Of the 31% female patients, almost all (82%) belonged to racial/ethnic minorities, including 69% AA. Baseline study participants were recruited between April 2010 and February 2011.

Qualitative data

Qualitative instrument development. The specifics of the qualitative data collection have been reported previously.^[6] In brief, the qualitative research guide was developed to capture the potential barriers and facilitators to engaging in HIV care at three time points: the decision to get tested and testing experiences (at diagnosis); early experiences in HIV care (early care); and more recent / contemporary care experiences (late care). The qualitative guide was pilot-tested among a group of non-research participants and revised for use.

Qualitative participant recruitment and consent. General recruitment (via posts, provider referrals) was followed by targeted recruitment of under-represented subgroups (younger, recently diagnosed). Recruitment details are available elsewhere (Quinlivan).

Both the UNC and the Duke University Institutional Review Boards approved consent and recruitment procedures. Informed consent occurred prior to the focus groups and individual interviews.

Qualitative data collection procedures. Both focus groups (2 focus groups comprised of 11 participants total) and semi-structured individual interviews (19 interviews) were conducted. The final sample falls within acceptable parameters for a qualitative research sample.²³ Focus groups were conducted by an experienced facilitator, who was also a woman of color; each took approximately two hours to complete (January-February 2010). Note-takers recorded field observations during the focus groups and expanded upon these notes following each session.²⁴ The semi-structured interviews occurred between February and May (2010); six were in-person interviews and 13 occurred by telephone. These semi-structured interviews were also facilitated by an experienced interviewer and took about an hour to complete. Data were digitally recorded, transcribed verbatim; transcripts were compared to the audio recordings and corrected for discrepancies.

Use of the Behavioral Activation Theory. From the qualitative coding, it was found that many of the women spoke of actions that were demonstrative of depressive behaviors. Yet in the quantitative findings, when using the PHQ-9 scale where the women have to identify these depressive symptoms, there was not a significant association. The disparities between the quantitative and the qualitative findings informed the decision to seek out a means of explaining why those disparities existed. This is in line with related ethnographic studies describing the difficulty that African-American women have in the identification

and naming of depression.^[4, 7, 13, 15, 23] Sole use of the PHQ-9 may not have sufficiently captured depression identification among these women. The Behavioral Activation (BA) Theory ^[19, 20] has been used to develop interventions for depression and hypothesizes that correlating factors (i.e. positive HIV diagnosis and other negative life events)^[14, 19, 20, 22] contribute to the development of depression and could be utilized in depression identification.^[19-21]

Qualitative data analysis. Grounded theory methodology guided the analysis²⁵ (insert “25” source cite here), during which specific themes related to women’s report of depression emerged from the transcripts. Data were analyzed using a systematic, manual open-coding approach to identify how women expressed their depression, the factors that contributed to or exacerbated their depression, and depression buffers; recurring themes were identified, discussed and modified until thematic saturation was achieved. Behaviors such as returning to using drugs after diagnosis, missing appointments because of shame guilt and embarrassment and thoughts of suicide or dying were common themes. Terms like “I was in denial” or “I haven’t been taking care of myself” or keeping oneself isolated were used by the women and seen often throughout the coding process. This modified grounded theory approach to analysis employed both inductive and deductive reasoning to inform the analysis.²⁶ Each transcript (focus group or interview) was independently read and content-coded by three members of the analytic team,²⁷ using traditional open-coding content analysis. Team members discussed the coding, identified areas of discrepancy and resolved them. Data dependability was further established by careful recording of the coding processes and frequent returns to the original language in the transcripts.

Quantitative data

Quantitative data collection. Serial cross sectional data were collected as part of the Guide to Healing evaluation, described previously.^[5] All English-literate WOC who attended their medical appointment on an interview day were approached to participate. The baseline response rate was 58%, baseline participants represent 47% of the total HIV-infected WOC in the clinic, and consented women do not differ from the clinic population on sociodemographic variables. The survey questions were read to participants by trained interviewers who entered their responses into netbook computers. Participants received a \$25 gift card for their time.

Quantitative depression outcome. The PHQ-9 was used to quantify depression symptoms. It is a validated and reliable 9-item survey designed to screen for potential DSM diagnosable depression.^[24] Respondents were asked questions regarding the symptoms experienced over the last 2 weeks and responded on a scale of 1 (“Not at All”) to 4 (“Nearly every day”). The PHQ-9^[24] was scored by summing the item values.

Quantitative correlates of depression

Barriers-related correlates. As described previously,^[5] we used a modified version of the Barriers to Care Scale.^[25] Interviewers asked respondents to indicate the extent to which a given barrier made it difficult to obtain medical care, specifically HIV clinic appointments and mental health services. The Medical Self-Advocacy scale captured communication with providers^[26] and response options to 12 questions were coded to

ensure higher scores corresponded to more active communication. The HIV Symptom Index ^[27] is a 20 question scale that asks about general health issues in the past 4 weeks. Anxiety and depression questions (n=3) were excluded since they were assessed separately. Responses to the HIV Symptom Index were summed, with reverse coding as appropriate to create a continuous variable.

Social-support-related correlates. Perceived emotional and practical social support available from friends and others was captured as a 7-item subset of the Social Support and Activities Scale.^[28, 29] The availability of support, care and guidance for HIV care was assessed using the Treatment-specific Social Support Scale (TSSS), which is a modified 12-item subset of the Social Provisions Scale.^[29] These social environmental scales were continuous covariates in our model.

Trauma-related correlates. The Index of Psychological Abuse Scale (IPA Scale) captured experiences of ridicule, harassment, criticism, and emotional withdraw from their partner.^[30] A trauma scale developed for use in a variety of settings (personal communication, K Sikkema, 2010) included childhood-specific and adult-oriented trauma questions. The childhood trauma subscale included 13 questions, while the adult subscale included 9. Higher values indicated more trauma and the social environment scales were used as continuous predictors in our model.

Substance use-related correlates. Separate questions asked about current drinking and ever drug use behavior. Current drinking asked women if they drank now, and response options were “yes” or “no”. Ever drug use asked women if they ever used prescription or non-prescription drugs for the purpose of changing the way they felt, with the same response options (yes or no).

Socio-demographic Variables. Participants reported their age, housing status, employment status, insurance status, relationship status, and years of education. Age was coded as a continuous variable, and education was categorized as having less than 12 years, 12 years, or more than 12 years of education. To include an additional indicator of personal resources, insurance status was dichotomized to private insurance and not private insurance.

Quantitative data analysis. Means and standard deviations of the continuous variables, counts and percentages of the categorical variables were created. Scale properties were examined, including Cronbach's alphas for scale reliability. Spearman pairwise correlations assessed the relationships among the scales. Linear regression was used to assess the relationship between the continuous depression outcome and potential correlates (barriers to care, medical self-advocacy, HIV symptoms, social support, treatment-specific social support, psychological abuse, childhood and adult trauma, substance use and socio-demographics). Models were adjusted for age, education, employment, housing and insurance status; beta coefficients and 95% confidence intervals are reported.

Quantitative Results

Most of the women included in our quantitative sample were over 40 years of age (72%), had 12 or more years of education (72%) and lived in permanent housing (89%) (Table 1). The vast majority had public or no insurance (83%) and were unemployed (71%). While most women were not current drinkers or drug users (69%), half had used drugs at some point (55%).

The PHQ-9 is a depression screening tool used for monitoring a patient's response to treatment. The PHQ-9 is scored 0 to 27, with scores ≥ 10 indicating a possible depressive disorder. It also includes a question to assess whether depressive symptoms are impairing function, a key criteria to establishing a DSM-based diagnosis ^[31] [cite]. Similar to other screening questionnaires, the PHQ-9 is not sufficiently accurate to establish a definitive diagnosis for depression, with both sensitivity and specificity at 88 percent. [24] In this study, it showed an acceptable level of reliability (Chronbach's alpha), with scores ranging from 0.8 to 0.9 (Table 2). The self-advocacy scale had the lowest internal reliability (0.6) while both the HIV symptom index and Index of psychological abuse had alphas of 0.9. The mean depression score among respondents was 3.1 (standard deviation 3.7) indicating low levels of reported depression.

In adjusted models, women who reported higher amounts of barriers, HIV symptoms, psychological abuse and adult trauma also reported more depression (Figure 1). Paradoxically, women who were more likely to advocate for themselves with medical professionals were also more likely to report higher depressive symptoms. Social support was inversely related to depressive symptoms, but treatment-specific social support was not statistically significantly associated. Among women who participated in the quantitative data collection, neither current drinking nor lifetime drug use was associated with depression reports.

Qualitative Results

Several common themes emerged as the women engaged in dialogue during the focus groups and in the one-on-one interviews. The viewpoints expressed sometimes overlapped but are intrinsically linked to one another.

Depression-naming dynamics

Study participants were more likely to name depression in the focus groups than during the one-on-one interviews. Several times during the focus groups, after one woman expressed depression by name, other women in the group would also share experiencing depression. In one focus group, for instance, a woman mentioned that she had suffered from depression since her mother died, after which another participant said: *"I suffer from the disease, from what you suffer from, too... I can relate to what you're saying about the depression."* Overall there seemed to be fewer expressions of depression in the one-on-one interviews than in the focus groups. During the interviews, women were initially hesitant to discuss feelings of depression and would use words that have been linked to depression, including isolation, stress, and having good days and bad days, instead of naming depression explicitly.

Recognizing and understanding depression

In both the focus groups and one-on-one interviews, women identified symptoms of depression. Sometimes women were able to acknowledge symptoms of depression without naming the emotional state itself.

“All I know is I got tested, and they told me, and I was upset. Ya know, I was real upset. And I wished I had a therapist then. Someone I could relate to, a case worker or something that I didn’t have at that time. Yeah. That would help. Right, right. Yes, I think that would give... Especially, as soon as you find out, I think they need to keep you close... You need to be able to talk with someone and to express your feelings. If you gotta: cry, get it out whatever... I’ve learned to deal with my feelings. I don’t stuff ‘em anymore. I feel ‘em and go on. If they hurt, they hurt. If they don’t, they don’t, ya know.”

Other times the women would cite depression by name: *“But one day I came to the doctor, and I broke down in the doctor’s office. And because I was... that depression was on me that day. And I came in, and she had me talk to somebody”* Both of these women were early in their care and while one woman seemed to understand what she was feeling to be depression, the other woman used words to describe an emotional state as outlined in the BA theory, representing but not naming depression.

Depression and stage of HIV care

Over the course of data collection, it became apparent that reports of depression, and its manifestation, differed by stage of HIV care at diagnosis, early care and late care. Early in care, women were more likely to attribute their depression to their positive HIV diagnosis, whereas later in care women tended to ascribe their depression to factors outside of their positive HIV status. One participant described hopelessness associated with

the emotional pain related to the HIV diagnosis: *“When I was first diagnosed...I felt like weren’t no sense in coming to the clinic.”*

In addition to hopelessness, stigma contributed to depression during in the early post-diagnosis period.

“It was hard for me. It was never easy from the first appointment because of the shame and the guilt and embarrassment. So it was hard for me to go to my second and third appointment.”

Later in care, other disruptions such as losing a home, co-morbidities to HIV, the stigma of being HIV positive and the long-term stress of being HIV positive, were reported as factors contributing to their depression. One participant lamented about her loss: *“I went through a transition in my life where I lost my home...I went through that depression”* and, *“it caused me to—Not to take care of myself like I was used to...”* In this case it appears that the loss of a home led to depression, which in turn led to a lack of self-care.

Lack of self-care

Lack of self-care was another common theme that several of the women expressed, resulting from depression occurring both early and late in their course of care:

“I basically just stopped eating and stopped sleeping. I lost about twelve pounds. I was just going crazy.” and *“...it [depression from becoming homeless] caused me to— not to take care of myself like I was used to”.*

Additionally, women reported using negative coping strategies such as drugs and alcohol to address symptoms associated with hopelessness. *“... I had started back using street drugs because I had got to the point where, well, if I’m going to die, I’m going to die*

anyway. So I'm going to go back to doing the things that I like to do, even though I was told to stay off the street drugs." There were several more quotes similar to these from women expressing turning back to drugs and or alcohol as a coping mechanism after diagnosis, causing them to use physically destructive avoidance behaviors as a response to the original negative life event (i.e. HIV diagnosis).

The role of emotional support

When prompted to think back on what would have been helpful to them early on in their care, participant's overwhelming response was "talking to someone"; for instance:

"Having someone to talk to... To explain to you what this disease entails... And if you have to have lab work, get that done. Somebody that's easy to talk to. For that first delivery is real important. People are scared to death!"

Another woman mentioned wanting to speak to someone in a medical capacity when first being diagnosed so that she could understand what was going on herself and then be able to explain it to friends and family:

"I guess somebody to talk to me. I really don't remember nobody coming out and explaining like what was going to be going on with me...I knew about it and I didn't tell my family or my friends, so it was kind of like living a double life...one [day]...I would be, okay, I feel like everything was fine, I didn't have to think about it, and then when I went to the doctors, it's like, 'Okay, I'm HIV positive, what am I gonna do?'"

Among women who were early in their HIV care, talking to someone usually meant a one-on-one type of interaction, such as speaking with a family member or a doctor or a nurse.

The idea of speaking in front of others usually took some time to get used to.

The role of support groups

In both focus groups and in one-on-one interviews, participants expressed that support groups were also helpful. Talking in a group dynamic, such as participating in support groups, came up among women who were later in their HIV care. The women recognized that these support groups provided a judgment-free platform for discussing depression and other important matters, with people they could relate to:

"...it's good to be around somebody livin' with the same thing you're livin' with, and can understand when you need to talk to somebody about what's going on, the depression behind it... because you do get depressed behind this."

Support groups not only alleviated women's feelings of isolation, but also aided in increasing the likelihood of women to attend their clinical visits. Here's a quote from a participant demonstrating the influence that being in a support group had on increasing her clinic attendance:

"Not wanting to go, not wanting nobody to see me in the clinics. Yeah, so that was kind of hard until I got used to them. I was also in a program...where women that are HIV positive and all of us had to come to the same clinic, so that made it a little bit easier having someone else with me. Then once I got to

know the people here in the clinic and know why they were here, they were here for the same reason I am, it got easier for me to come... a whole lot easier."

Knowing that there were other women experiencing similar issues, seemed to help many of the participants overcome feelings of self-isolation and supported their transition to healthier behaviors.

"I started going to a private therapist and I also found a support group. I finally worked up the courage to start going to a support group and that was really nice just talking to someone else that knew what I was going through and could relate to some of the issues that I was having. I could go to them and talk or cry on a shoulder when I needed it because, you know, I've had some really rough times. I had to start back on an antidepressant so... but even though I had to go through that too, they were always there to comfort me kind of thing and help me with my daughter..."

Self-care as a buffer for depression

While many of the women reported having someone to talk to as being most consistently helpful in overcoming depression, other buffers were helpful as well. Women who were later in care, and more settled into their diagnosis, seemed more aware of taking care of themselves. Some reported becoming more intentional about their HIV management:

"...once I got help with drugs, I decided that being healthy in my body, mind, and spirit, I had to do something about my HIV. I talked with a lady... where I went to treatment at, and she helped me to get into UNC Chapel Hill, and that's when

I started coming here.” While others turned more to taking care of their health more generally: “I walk. I exercise. I eat right. I meditate. And I work. And I talk about what’s going on with me. If I’m feeling down and depressed, I’ll call my family, brother, I talk to my husband, I talk to my sister, my aunts, that’s what I do to take care of me.”

Attending HIV visits was regularly named as a self-care strategy against depression for the women who participated in the qualitative data collection: *“I want to live. And I enjoy the atmosphere, I like seeing people, and then my doctors and my social worker, I like seeing them. When they see me, they know I’m doing good, and it makes me feel good, and I know I’m doing good.”* Women who were later in their care seemed to have a more solid grasp of what was required to take care of themselves and remain in care as opposed to returning to previously utilized detrimental avoidance behaviors (i.e. not caring and missing appointments, doing drugs and isolating themselves) that may have led to depression.

Integrating the quantitative and qualitative results

Many of the relationships observed in the quantitative data were spontaneously represented in the women’s qualitative reports. Specifically, this study found the importance of social support as a buffer for depression and poor health. And higher perceived barriers to care were the primary contributing factors to self-described depression. Both drug and alcohol use were identified as being associated with depression qualitatively, but in the quantitative findings, a statistical association was not present.

Discussion

In this mixed methods study of HIV infected women of color, women reported experiences with depression directly and indirectly. Depression was identified by the women as a consistent theme in the qualitative studies and was associated with barriers to care quantitatively. Consistent with prior work, both qualitative and quantitative results demonstrated that social support was a protection against depression, [4-6, 11, 12, 20] with women spontaneously naming social support as being a buffer in the focus groups and interviews.

Depression identification differed by stage of HIV care. *At diagnosis* proved to be a critical time for many of the women. [4, 12] They often expressed denial of their HIV positive status or a return to some of the negative habits [14, 18-21] that may have contributed to contracting HIV. Also at this stage, many of the women did not use the terminology “depression,” but rather spoke of their negative behaviors [12, 18, 19] (i.e. drug use, denial, avoiding care appointments) at the point of diagnosis. Guided by the BA theory, we extrapolated from women’s words and reported actions to identify probable depression, even when they did not use that language explicitly. [4, 15, 19, 20] *Early in HIV care*, women reported they were more likely to acknowledge their positive HIV status and were beginning to find different ways to address and prevent depression, via support groups and more social support (i.e. family and friends). However, women reported moving through those early stages with trepidation while still seeking a system of care that would work for them and would allow for healthier expressions. *Later in care*, once the women had come to accept their HIV+ status, they spoke more freely of their ability to ward off depression (i.e.

buffers) and were learning to appropriately address depression when it occurred, for example, by exercising, eating right and seeing a private therapist. These behaviors helped them to maintain their health status and stay in care.

While women's qualitative accounts suggested a strong association between substance use and depression, we did not observe a statistically significant association among the women who completed the quantitative questionnaire. There are a couple of possible reasons for this unexpected finding. First, because the qualitative data from women described depression associated with active substance use. However, in the quantitative data the substance use was both current and historical but the depression was only assessed as current. Additionally, the women we interviewed were actively in care, and those who did not participate in these interviews, or may not be currently in care, may have more substance-use related depression. Previous reports indicate that women (as opposed to men) may be less likely to report current substance use and may have chosen not to participate in interviews [Pence, 2005, Validation of SAMISS].

There was found to be a strong association between the self-advocacy scale and depression. It was not immediately apparent (based on quantitative results), where the women who felt better able to advocate for themselves, while also reporting higher symptoms of depression, were in their care. However, from the qualitative coding, the women who were *later in care* also seemed to be the ones advocating for their long-term health care while also being able to verbally identify depression by name.

While provocative, this study is not without limitations. One limitation results from the two methods used to collect the qualitative data, the focus groups and the one-on-one interviews. In the focus groups, when one women mentioned depression as being a barrier

to care participation, others would concur or contribute similarly. This dynamic was not possible in the one-on-one interviews because – in an effort to catch spontaneous expressions – there were no depression specific questions. The consequence of this data collection dynamic is a likely underrepresentation of depression among the women who participated in the one-on-one interviews. A second limitation is that while the participants came from the same clinic population, we did not collect identifiers or create study identifiers for the qualitative data participants. Therefore, the women offering the qualitative perspectives and the women representing the quantitative findings may not be the same women. This is not a significant problem, as these complementary perspectives about depression seem to reinforce each other. Also, as noted previously, the women that participated in these interviews are women who are in care and receiving clinical services. It is possible that the women who struggle the most with depression, especially given the reported association between self-neglect and depression are not currently in care.^[4, 7, 14] A further limitation to this study includes these data being cross-sectional, which means the direction of causation between depression and the depression correlates, is uncertain.

Although limited, the study has several strengths that we believe ensure it will contribute positively to the literature. The use of mixed methods, to get both the amount of depression and description of depression and its correlates, contributes a robust finding to the literature. This large quantitative sample ensures its broad representativeness of HIV positive WOC in the NC area. A consistency of themes within our own study among participants and in other published work when it comes to recognizing depression as a barrier to care^[4, 11, 12, 18] is another strength of the study. And further, use of the BA theory

can assist in identifying depression on a broader scale, by recognizing depressive symptoms through negative behaviors when depression isn't being explicitly named.^[14, 19]

Implications for HIV care

Expansion of the instruments used to identify depression (i.e. PHQ-9) is needed to ensure that they are identify depression as efficiently as possible in African American women. Several of the instruments use the word "depression" in the depressive identification. And because it has been found that African American women often associate the use of the word "depression" with weakness^[4, 16] and have a difficult time recognizing and reporting depression as compared to other populations, it may be worth using alternative instruments that does not use depression as part of the questionnaire; or possibly the design of a culturally-tailored depression identification instrument. The discrepancies that we found between the quantitative data and the one-on-one interviews and the focus groups in identifying depression supported prior works ^[15, 32] in the difficulties associated with depression identification among WOC.

It is known that depression alone can contribute to the difficulty in accessing healthcare ^[4, 15, 32]. We are also learning more about the difficulty that WOC have in identifying and acknowledging in themselves, or by instruments of self-report. By understanding that depression is often a compounding factor in women with HIV, then understanding the correlation between WOC with HIV and depression may help the practitioners to identify depression by being watchful for behaviors expressing depression without relying solely on the instruments of self-report currently in use. The use of a

culturally specific depression-identification instrument may also help increase the efficacy of the depression tests being administered.

Because of the difficulty in retaining women of color with HIV in care, by understanding that depression acts as a barrier to care, it may be worth studying where in the HIV care continuum WOC with HIV are at most risk of falling out of care. Our qualitative findings showed that more women discussed being in denial (of having HIV) or not returning to care, *at diagnosis*. We believe that it is imperative that depression is identified as early as possible in order to identify the women at highest risk for falling out of HIV care. We also believe that health care practitioners will be more successful at retaining HIV-positive women of color in care if we can identify – and intervene upon – depression as early in care as possible.

Once depressed women are identified, interventions that direct these women into support groups may be helpful; prior work, found that social support and support groups have a positive correlation with WOC with HIV and care engagement^[4-6, 32]. We recommend that health and mental health providers strive to better understand and acknowledge how the AA woman's cultural experiences and perceptions of depression help to inform how depression manifests in these women. And in working with the practitioners to develop a means of communicating with these women using culturally specific verbiage that doesn't immediately implicate depression, so as to avoid denial or avoidance behaviors.

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TABLE 1. Sociodemographic characteristics of women enrolled in the baseline sample of the Guide to Healing study (n=189).

Socio-demographic Characteristics

Age	N (%)
Continuous age [mean (sd)]	46 (10.4)
<30	12 (6.4%)
30-39	41 (21.7%)
40-49	67 (35.5%)
50+	69 (36.5%)
Education Years	
Continuous education [mean (sd)]	12.0 (2.0)
< 12 years	53 (28.0%)
= 12 years	69 (36.5%)
>12 years	67 (35.5%)
Insurance Status*	
Not private	157 (83.1%)
Private	26 (13.8%)
Employment Status	
Unemployed	134 (70.9%)
Full or Part Time	55 (29.1%)
Housing	
Non-permanent or institution	21 (11.1%)
Permanent	168 (88.9%)
Current drinking	
No	130 (68.8%)
Yes	59 (31.2%)
Ever drug use	
No	86 (45.5%)
Yes	103 (54.5%)

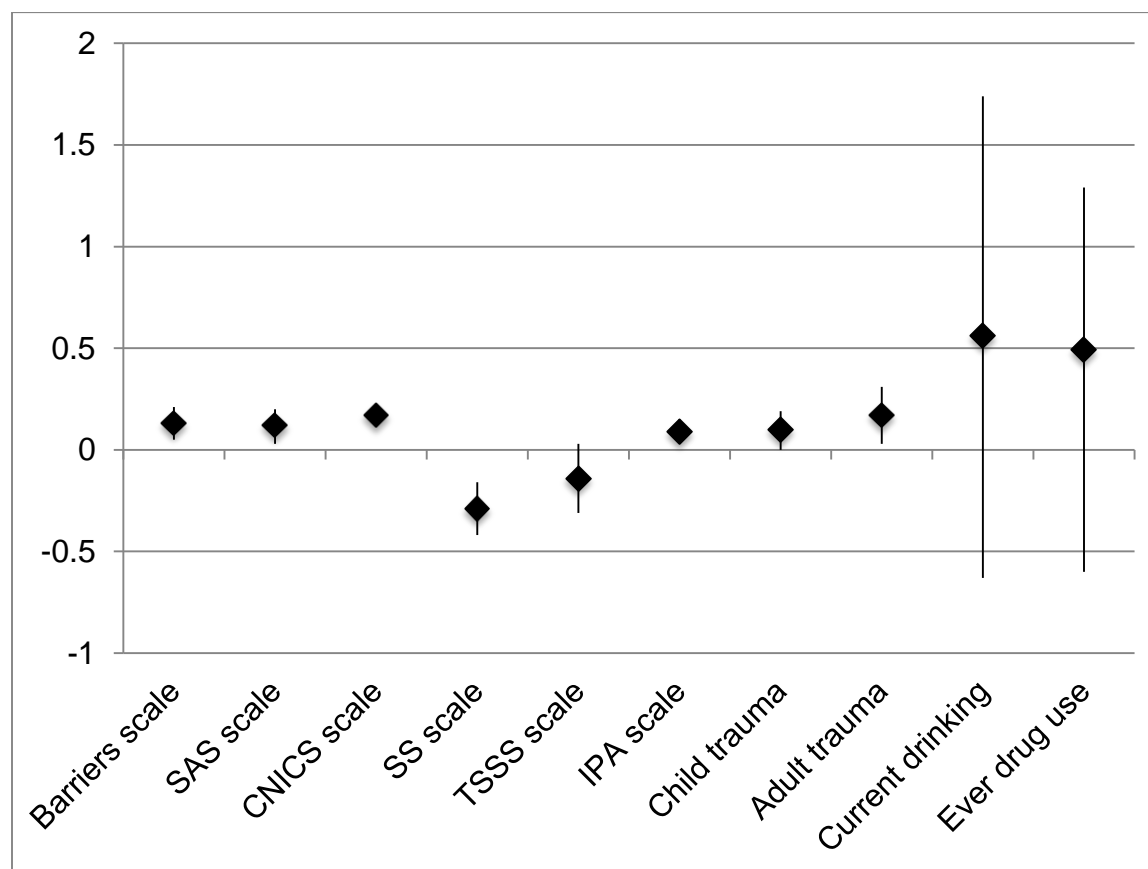
* missing = 6 (3.2%)

TABLE 2. Sociodemographic characteristics of women enrolled in the baseline sample of the Guide to Healing study (n=189).

Continuous scale	Mean (sd)	Theoretical range	Observed range	Cronbach's alpha
Barriers to care*	19.7 (7.4)	11-44	11-40	0.85
Self-advocacy scale	44.3 (6.2)	12-60	24-59	0.64
HIV symptom index	21.5 (13.5)	0-68	0-54	0.90
PHQ-9	3.1 (3.7)	0-27	0-16	0.80
Social support	24.0 (4.1)	7-28	7-28	0.84
Treatment-specific social support	32.3 (3.3)	12-48	21-43	0.87
Index of psychological abuse (IPA)*	32.7 (10.9)	21-84	21-63	0.90
WHO trauma scale (child items)	19.9 (5.4)	13-52	13-38	0.80
WHO trauma scale (adult items)	15.2 (3.9)	9-32	9-27	0.71

* Barriers to care and IPA scales were only assessed from April 2010 to December 2010 and n=156 and 152, respectively.

Figure 1. Beta coefficients and 95% confidence intervals estimating associations among depression outcome (PHQ-9) and correlates (barriers-related, social support, trauma-related, and substance use), adjusted for categorical housing, employment, insurance, education and continuous age.



APPENDIX A:

PORTLAND BRIDGES TO BACCALAUREATE TO HONORS COLLEGE THESIS

In the spring of 2014, I was a student at Portland Community College expressing an interest in research. It turns out that I must have apparently expressed my interest to the right person because only days later, I found myself writing an application letter for entrance into a program called the Portland Bridges to Baccalaureate program. This was a program geared towards increasing the diversity of highly trained, biomedical research personnel dedicated to investigating and alleviating health disparities. At the time, I had no idea that this single event was about to change my life. Within a very short period of time, I had gone from “being interested in research” to being accepted into the internship program to shortly after that, being introduced to Dr. Lynne Messer as my mentor and adviser.

When I entered Dr. Messer’s office at Portland State University, I was unsure of what to expect. On the first day of our meeting, I was handed an online file that included fifty-two pages of the project grant titled “Guide to Healing: Enhancing Access for HIV+ Women in the Rural South.” I was also handed the qualitative interview guide, nineteen one-on-one interview transcripts – each about 15 to 20 pages in length, and two focus groups transcripts – each about 35 pages in length. I had no idea what to do with any of the information before me, but Dr. Messer just told me to start reading, so I did. It took me about a week to get through all of that information (I was working about 3-4 hours a day at the time). When I finished reading everything, I was so proud of myself. I walked into Dr. Messer’s office and declared that “I was done!” and promptly asked “what’s next?” silently thinking that this research thing was a piece of cake! Well, Dr. Messer just smiled at me,

because she knew what was next. She then said to me “now, you get to read it again!” This was *the* moment that I understood this was just the beginning.

Over the course of the summer, I learned how to read through transcripts and glean the data applicable to our subject matter. I learned how to code the data from the women’s interviews into various themes, how to read those interviews with a discerning eye when it came to searching for depression behaviors, if the word depression wasn’t explicitly named. And also I learned to trust myself to know what those depressive behaviors looked like when I found them in the transcripts. I spent much of the summer coding those themes and creating a chart for each question asked by the interviewer in a semi-structured interview format. Those charts were divided into sections headed “Theme” and “Quote” where the themes were recorded along with the quote and the interview number or focus group that the quote came from and the woman’s coded number who made the statement.

Here’s an example of what those charts looked like:

Q1: Think about the last medical appointment that you kept. So, the last medical appointment that you had, and you came to, you kept it. What made it easier to keep? What’s something or some things that made it easy to keep?

THEME	QUOTE
Genuine Caring Doctor FG1/ R5: Conseq/ Diag Buffer/ Late	FG1/ R5: It’s important to me because, I really hadn’t been taking care of myself for ten years when I had HIV. I was in denial. So now when I see my doctor, I’m very proud that he got me on something to keep me alive. And he’s really very devoted, you know, very [competent?] doctor to talk to. Yeah.
INT14: Ashamed	INT14: The staff, like, everybody is – I built a relationship up with them, so it’s just so much easier, like they know my situation, what’s going on with me, and they’re so willing to help me and despite of what I’ve been doing and make me feel very comfortable. You know sometimes I, a lot of times what kept me from not coming is I’m a recovering addict, so I would get high, and I would stay out

	because I'd feel so ashamed and I didn't want to – and I already knew they knew I was getting high because I missed my appointment. But I kind of felt like if I didn't come, then I would still be hiding or something, like say –
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In this quote, the women were only identified as R5/FG1 (translation: responder 5 from focus group 1) and INT14 (interview 14). The common theme of both of these quotes is “Genuine Caring Doctor” in response to the question and the first half of the first quote demonstrates an example of the behavior exhibited by the responder before she realized that the doctors cared (at diagnosis/ consequences) and the second part of her quote is the behavior displayed after her realization later (buffer/ late). The first part of the quote is seen as avoidance behaviors that are often exhibited by persons with depression and the second half is referring to what helped her to get into care and stay in care, also known as a “buffer.”

After gathering quotes demonstrating expressions of depression and depression behaviors, I found that the responses were different based on where in care the women were asked to recall, and that the behaviors varied by where they were in care at the time of the interview. This is when I began to understand that *at diagnosis*, *early in care*, and *late in care* meant. The women were prone to take care of themselves and learn behaviors in order to protect themselves against depression or to help ward off depression and these were called *buffers*.

At the end of the summer, with the help of Dr. Messer, I created a scientific poster documenting the work that we had accomplished and presented our data at a conference for the Portland Bridges to Baccalaureate cohort, alumni, faculty and advisers and PSU President Wim Wiewel was attendance for the presentation. Dr. Messer and I both agreed to continue working on the document and continue to groom the findings into a journal

publication. Within the past year or so, we have refined the data findings and discovered the use of the Behavioral Activation Theory in depression identification for use when depression behaviors are present and yet the acknowledgement (or self-report) of having depression is lacking.

In the spring of 2016, another poster was created for the Oregon Master of Public Health (OMPH) Student Poster Showcase. This poster was of the same title as this thesis. This poster documented the current findings using ethnographic information regarding women of color and depression behaviors and how the use of the Behavioral Activation Theory in depression identification can be of use. This poster won one of the “Outstanding Poster” awards at the conference.

The qualitative data findings along with the use of the Behavioral Activation Theory were undertaken by myself along with advisory assistance from Dr. Lynne Messer. The quantitative data used for the poster and the poster presentation, used variables such as social support, treatment specific social support, index of psychological abuse, drug abuse and alcohol abuse, and determined their correlation to depression by levels of education (>12y, =12y, <12y) and age (<30y, 30-39, 40-49, 50+). I configured those regression tables using data analysis statistics software, using a 95% confidence interval. For thesis publication, Dr. Messer configured the quantitative data analysis used in Table 1, Table 2 and Figure 1.

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